



# U.S. Senator Judd Gregg, Chairman

## Senate Committee on Health, Education, Labor and Pensions

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### **Senate HELP Committee Passes Bipartisan Bill to Protect Against Genetic Discrimination**

Years of Work Culminate in Unanimous Passage of Bipartisan Bill Today

**Washington, DC**—After six years of effort, the Senate HELP Committee under the Chairmanship of Senator Judd Gregg (R-New Hampshire) reached agreement on and passed a bipartisan bill to protect the privacy of genetic information and to protect individuals from discrimination on the basis of genetic information in hiring, employment and health insurance. The bill passed the committee unanimously by voice vote this morning.

“The legislation we are passing today fulfills the promise of the Human Genome Project. It establishes in federal law basic legal protections to enable and encourage individuals to take advantage of genetic screening, counseling, testing and new therapies,” said Chairman Gregg.

“The bill protects the privacy of genetic information. And it protects individuals from discrimination in health insurance or employment, based on their genetic information. It ensures that a woman with breast cancer and the healthy daughter who shares her genetic predisposition for the disease are both protected,” said Gregg.

“I am also pleased that the first civil rights legislation adopted under my chairmanship deals with an issue of truly 21<sup>st</sup> century concerns. From the past we have learned that employees, employers, insurers and others all work best together when the rules are clear and opportunities for personal achievement are open. It is my hope that the bipartisan spirit that brought the parties together to craft this historic legislation will continue as we seek to confront the many challenges facing our workplaces today,” Gregg said.

“Today public policy catches up with science to ensure that all Americans can realize the promise of advances made in the field of genetic science,” said Gregg.

A summary of the bill is included below:

#### **S. \_\_\_, Genetics Non-Discrimination Act**

##### **Protects against genetic discrimination from health plans and insurance companies.**

- Prohibits health insurance plans from denying an individual enrollment in the plan because of individual's or family member's genetic information.
- Prohibits health insurance plans from charging higher premiums to individuals because of individual's or family member's genetic information.
- Prohibits health insurance companies from basing premiums of a group health plan on genetic information of members (including family members) of the plan.

**Keeps genetic information private:**

- HHS privacy rules govern the use and disclosure of genetic information, except this bill also:
- Bans the use and disclosure of genetic information for insurance underwriting purposes.
- Bans the collection (i.e., requesting, requiring, and purchasing) of genetic information for purposes of underwriting.
- Prohibits insurance companies from collecting genetic information prior to enrollment in any plan.

**Structure and Enforcement of Health Provisions:**

- Creates a single federal standard for protection of genetic information, which does not exist today.
- Generally builds on the existing law framework under HIPAA. In doing so, this ensures that genetic information is treated consistently with other health information and individuals, who face discrimination, whether they are healthy, sick or disabled, have the same rights and remedies.
- The non-discrimination provisions are enforced in same manner as current law, however some procedural protections are established for group health plan participants including the ability to seek injunctive relief and to have retroactive reinstatement of coverage for violations. Penalties may be payable to the individual or levied against the plan.
- The privacy provisions are enforced in the same manner as HIPAA privacy rules through HHS Office of Civil Rights; with the same civil penalty and criminal enforcement structure.

**Protects employees from genetic discrimination at the workplace:**

- Prohibits the use of genetic information in employment decisions, such as hiring, firing, job assignments, and promotions.
- Prevents the acquisition and disclosure of genetic information.
- Applies the same procedures and remedies as other forms of employment discrimination, such as race under the Civil Rights Act of 1964 and disabilities under the Americans with Disabilities Act of 1990.

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